Impact of Severe Childhood Epilepsy on Siblings: Interim Findings from the Sibling Voices Survey

Laurie D. Bailey¹, Arnold R. Gammaitoni¹, Bradley S. Galer¹, Lauren Schwartz², Carla Schad¹
¹Medical and Scientific Affairs, Zogenix, Inc., Emeryville, CA, USA 94608
²University of Washington, Department of Rehabilitation Medicine, Seattle WA 98195

Laurie Bailey, Presenter
Dr. Kelly Knupp, Session Moderator

DSF Conference
July 20, 2018
Disclosures

- Laurie Bailey is a salaried employee of Zogenix, Inc. and maintains stock ownership with Zogenix, Inc.

- This sibling survey and data generated were sponsored by Zogenix, Inc.
Introduction

• Dravet syndrome (DS), Lennox-Gastaut syndrome (LGS), and other severe childhood epileptic encephalopathies (EEs) require comprehensive care

• Burden of care
  – Emotional impact on immediate caregivers affects the quality of life of the entire family unit\(^1\)

• Impact on the siblings of EE patients
  – 74% (114/154) of caregivers reported concern for sibling well-being

• The Sibling Voices Survey was developed to assess the psychosocial impact of growing up with a sibling with DS, LGS, or other severe childhood EE

How it all started

• Parents sharing family stories at DSF events
• Insight from 1:1 PAG meetings and ad board
• Identified unmet need and vetted idea through DSF
• Recruited core project team; DSF & LGS caregivers & siblings, psychologist, Zogenix MA executive team
Methods – Survey Development

• Online, age specific surveys
  – Siblings 9-12 years
  – Siblings 13-17 years
  – Adult siblings ≥18 years
  – Parents

• Developed and beta tested in consultation with DS and LGS patient communities and healthcare professionals

• Approved by the Western IRB (Puyallup, WA)

• Participants recruited through patient advocacy websites, social media, medical meetings, and patient community events

Obtained subject or caregiver consent
Survey Participants (n=248)

Sibling ages 9 – 63 years old
n=120

- 62% female
- 38% male

Respondents:
- 1 sibling – 90%
- 2 siblings – 8%
- 3 siblings – 2%

38% Siblings with Dravet
12% Siblings with LGS

(representing 107 epilepsy patients)

Parents
n=128

- 91% Moms
- 8% Dads
- 2% other

Most (81%) married

28% relocated for healthcare reasons

(representing 115 epilepsy patients)
• > 50% of respondents in the 9-12 Years and adult groups reported feeling down or unhappy sometimes or a lot

• A substantial portion of respondents reported sadness

• Parents perceived significantly lower levels of unhappy or sad mood symptoms than what was reported by siblings
Free-Form Responses Suggestive of Depressed Mood

“I feel guilty because I am the older sibling for him and a role model but I don’t think I’m doing a good job.”

“When I think about it sometimes I start to cry and it makes me upset.”

“...makes me feel guilty and also angry that I have to feel like this.”

“My concern for my parents has caused a lot of stress for me.”
Anxiety Symptoms: Composite Scores

Sibling responses to questions regarding stress and anxious mood suggest this is an at-risk population.

As with depressed mood, the 13-17 Years cohort reported less anxiety than other sibling cohorts.

As with depressed mood, parental perception of sibling’s anxious mood symptoms was significantly less than what was reported by siblings.

*Parent = YES/NO response: included if both YES
Free-Form Responses Suggestive of Anxiety

“I try to spend some time reading or listening to music to calm me down.”

“I love doing sports to get my mind away from all the drama at home.”

“It scared me and caused me a lot of stress that I did not believe I should share with others. I kept it to myself and it made me shut people out.”

“Their stress and frustration are contagious and it sits like a dark cloud above our heads.”
Sibling Session Insights

**Emotions—**
- Fear related to the siblings having seizures and that Dravet sibling might die
- Overwhelmingly emotional (able to calm after talking about fears)
- Anger at situation and/or at Dravet sibling
- Some siblings seemed more detached from the situation than others, most very expressive
- Stress regarding the family’s financial situation
- Very proud of sibling with Dravet

**Knowledge—**
- Significant knowledge about epilepsy; stated desire to understand more—as much as possible
- Likes talking to other kids about seizures, sharing their experiences, mentoring others
- Parents don’t share everything—kids don’t want them to hide anything as it makes kids more afraid
Sibling Session Insights

Non-affect sibling relationships—
• Sibling rivalry with non-affected sibling
• In households with multiple non-affected siblings, non affected siblings are nicer to Dravet sibling, causing friction between non-affected siblings
• Some non-affected siblings closely bonded, protective of each other (notice this when there is a much larger age difference between non-affected siblings)

Sleep—
• Sleep issues (not able to fall/stay asleep)
• Some reported no sleep issues at all (when Dravet sibling sleeps with parents)
Sibling Session Insights

When seizures happen—
• Common response is to remove themselves from the situation when seizures happen
• Most know how to help during an emergency situation (still desire more knowledge)

Other—
• Some expressed needing more time with parents (age dependent)
• Some are comfortable with parents spending more time with Dravet sibling
• Many siblings stated they were able to participate in extracurricular activities
• Ability to show empathy to non-affected siblings whose Dravet siblings are much lower functioning
Summary of feedback: SPNS Presentation

• Most clinicians indicated that siblings attend clinic/hospital visits

• Few clinicians inquired about the parents well-being; very, very few focused any attention upon the non-Dravet sibling

• Most clinicians were not surprised about the data; but were impacted/reminded about the potential unmet needs of the non-Dravet sibling

• Many clinicians from this meeting vowed to have increased focus on the non-Dravet sibling and family during patient interactions in both Epilepsy and other devastating neuro disorders
Adult Sibling Panel Discussion

Lilah Goodliffe
Lilah is 21 and going into her fourth year of studying psychology at the University of Reading, in the U.K. She has just completed a placement year working to treat young people with a diagnosis of anxiety or depression, using Cognitive Behavioural Therapy (CBT). She hopes to pursue career in clinical psychology, this has largely been shaped through her personal experiences of having a sibling with Dravet Syndrome (Theo, aged 15). She is passionate about helping families, especially siblings, of those with Dravet.

Danny Stanley
Danny is a Junior at the University of Wyoming, whose sister, Emily (18), has Dravet syndrome. Danny works in the Sun Neuroscience Lab and does research in intractable epilepsy, winning an INBRE (IDEA Network Biomedical Research Excellence) Fellowship and is in the WRSP (Wyoming Research Scholars Program). Danny recently presented his research at the Wyoming Research Days and works in a internship position in the lab full time during the summers. He was awarded the CURE Education Enrichment Fund Award and the Healthline and NORD Stronger Scholarship. Danny’s future plans are to continue working in epilepsy research to provide a better quality of life for patients with Dravet syndrome and other types of intractable epilepsy.

Kelli Stanley
Kelli Stanley’s sister, Emily, has Dravet. Kelli graduated from the University of Dayton with a Bachelor of Science in Biology this past May. She is currently applying to Physician Assistant school and will be attending Fall of 2019. Kelli loves sports, outdoor activities, and hanging out with friends and family.
Updates and Future Directions

• Siblings warrant assessment, monitoring, and potential intervention for depression and anxiety

• Clinicians should discuss potential for sibling depressed mood and anxiety with parents

• Even though it may be difficult, parents and siblings should try to keep an open dialogue to discuss concerns and/or fears

• Further research to consider how to help parents identify signs suggesting depression and/or anxiety in siblings and intervention strategies

• Create resource tools that are accessible to siblings 24/7
Sibling Book Project

• Written for siblings, by siblings

• The purpose of this book is to make Dravet syndrome and all the tough concepts that come along with it approachable to kids, as well as provide insight from other siblings who have lived similar experiences

• Initial project to be kicked off today during the Sibling Session

• Day of Dravet 2018 Regional Workshop Sibling Sessions will focus on the sibling book project

• Through social media, all Dravet siblings will have the opportunity to contribute
Thank you!

A heartfelt thank you to all the incredible siblings! YOU ARE AMAZING!

Be a part of a new, ground-breaking research study for siblings of epilepsy!

Raise your voice!

participate in the SIBLING VOICES SURVEY
Sponsored by Zogenix, Inc.

GO TO: www.siblingstudy.com to learn more about this survey

This survey will help us learn more about what it is like to have a brother or sister with severe epilepsy so that tools can be created to help families cope